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Patient and public involvement in systematic reviews

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Key messages of this chapter

- Patient and public involvement (PPI) is important to ensure that [systematic reviews](#) are relevant and meaningful to people affected by a health condition and people using systematic reviews to inform health policy or practice.
- There is no set formula or single method of involving people in a systematic review, nor is there evidence that any one way of involving people in a review is any more or less impactful.
- Several different factors will influence the decision on the best approach for a specific systematic review, including (but not limited to) the aim of involvement, the people who are being involved, and the resources and time available for this.
- PPI may be useful at any (or all) stages of a systematic review.
- There should always be a clear aim associated with involvement of people within a systematic review. Often this aim will relate to decisions that need to be made within the systematic review process. Depending on the aim of involvement, people may be involved at 1 stage, at 2 or more stages, or they can be involved throughout the whole review.
- Involvement of people in a systematic review can be considered as a continuum, from more involvement and control, to less involvement and control. But there is no evidence of a hierarchical association between level, impact, benefit or success of involvement.
- Different levels and methods of involvement may be useful at different stages in a systematic review.
- PPI in a systematic review should be clearly reported.

Terminology: systematic review

A systematic review is a type of research method that brings together evidence, generally from research studies, to answer a pre-defined research question.

Top Tips

- Plan PPI in a systematic review prior to working on the review protocol. This is because involving patients and the public in the protocol is a good way of making sure your final review addresses what is important to people with lived experience of a health condition.
- Planning should consider the project budget and payment of people's time or expenses, provision of training, and whether ethical approval is required. You should consider the availability of these resources when deciding who you can involve and how.
- Have a clear aim for involvement of patients and the public, and decide in advance what level of control that those involved will have over decision making within the review. Make sure that you communicate this clearly at the outset of the review.
- Good communication is a key to success when involving people in systematic reviews. This means it must be timely, use clear language, and use a method that suits the people involved.
- People can be involved at any (or all) stages in a review. When people are involved will depend on the aim of involvement. Involve people at:
 - the initial stages of the review (that is, protocol), to form the review question and scope
 - during the review, to contribute to searching, study selection, and collecting and analysing data
 - the final stages of the review, to support interpretation of the findings and dissemination of the review.
- Who you involve, and when and how you involve them, should be decided taking into account the topic of the review, the resources available, and the experience of the review team.

- Have a conversation as early as possible with everyone involved about any resources they need, including financial payment for their time.
- For systematic reviews that are being planned and conducted as part of a guideline development, a top and tail approach could potentially fit efficiently within the guideline process.
- Adopting a formal research method or process can be useful when there is a clearly identified role, or aim, for the people involved.
- The [ACTIVE framework](#) and the [GRIPP2 \(Guidance for Reporting Involvement of Patients and the Public 2\) checklist](#) (Staniskewsa et al. 2017) can be helpful for describing the planned involvement and reporting the actual involvement.

Aims of this chapter

This chapter aims to:

- highlight the importance of [planning](#) patient and public involvement (PPI) in a systematic review
- describe [who](#) you might involve in your review
- describe the [stages](#) when you might involve people
- describe the different [levels](#) of involvement you might have
- describe [how](#) people can be involved in a systematic review
- provide a framework for [describing and reporting](#) how you involved people
- signpost readers to a range of [resources](#) for further information.

Planning involvement in a systematic review

PPI and protocol development

A key stage in any systematic review is writing a detailed systematic review protocol. The protocol lays out details of the scope and design of the review, and the methods that will be used to conduct the review. Preferably, a systematic review protocol will be made freely available before the start of the systematic review. This lets people know what you are planning and helps avoid duplication of effort (that is, someone else carrying out the same, or very similar, systematic review).

Ideally, there will be PPI at the protocol development stage for the systematic review. It is good practice to have PPI contributors as core members of the review team. They play a key role in helping to plan how to involve additional PPI contributors throughout the review process.

The systematic review protocol should describe the planned PPI. In particular, the protocol should give details of:

- who will be involved, and how these people will be found or recruited
- when (at what stages) within the review process people will be involved, with a clear aim of the involvement at these stages
- how these people will be involved in order to meet the stated aim(s).

It is important to consider the key principles for good practice in involving people at the planning stage. The following issues are central to PPI in any research activity, including a systematic review:

- supportive and positive relationships
- clear and timely communication
- the roles and expectations of everyone involved, which should be discussed and agreed in advance of any involvement
- skills, knowledge and training (of researchers as well as of the people they involve) needed
- clarity regarding time commitments and requirements.

The project budget and payment for people's time or expenses, provision of training, and whether ethical approval is required must also be considered. The availability of these resources will influence who you can involve and how.

The Cochrane Consumer Network has published a [Statement of Principles for Consumer Involvement in Cochrane](#) to guide PPI. It highlights the importance of equity, inclusion and partnership. Communication and organisation are central to successful PPI, and it is important for researchers to consider practical points, such as accessibility (of meetings and materials) and having a clear point of contact for the people who are involved.

Choosing who, when and how for your review

There is no set formula or single method of involving people in a systematic review. Factors that will influence decisions around the best method for a specific systematic review include the:

- Topic of the review, and the people who may be affected by the results of the review.
- Aims of involving people. There may be a very specific aim to be met by involving people, such as informing the review outcomes, or supporting the dissemination of review results.
- Time available to do the review.
- Money available to support the review and involvement of people in the review.

- Expertise of researchers, and their experience of involving people in research.
- Preferences of the individuals involved.
- Desire for review findings to be locally, nationally or internationally generalisable.

A review may focus on a topic of national importance, and consequently the methods of involvement could focus on gaining involvement across that individual nation. Alternatively, a review may be internationally relevant, so it may be appropriate to gain international views and opinions.

Although the research team commonly makes the decisions on the plan, there will ideally be PPI in reaching the plan for the methods of involvement in the review. It is essential to consider the views and perspectives of the individual people who get involved, and to be prepared to be flexible and adaptive to the needs and suggestions of the people involved. For example, although you may have pre-planned 1 large workshop to reach decisions on outcomes important to a review, this format may not be accessible to some people and you may need to adapt your plans. If you are asking people to read or comment on written documents it is important to find out whether any of the people involved have specific requirements to facilitate accessibility, such as larger font sizes or audio versions. When seeking people to get involved, you may consider circulating requests for involvement in a variety of formats to promote accessibility. For example, you could circulate an audio description alongside a written description of the project. Being flexible and responsive, and working in partnership with the people who get involved is important to ensure equity and inclusivity.

One review can use a variety of different methods, each of which have a different approach to involvement, with different role classifications, and different levels of involvement. The following sections discuss key things to think about when planning PPI in your systematic review.

Who to involve in a systematic review

It is important to consider who the stakeholders for your systematic review are, and to involve representatives of key groups of people. Key groups to consider include:

- patients and their family members

- carers
- healthcare professionals
- health policy makers
- health funders
- decision makers working in the relevant field.

For a systematic review being conducted as part of a guideline development, the stakeholders for the review may be identical to the stakeholders for the guidelines. However, there may also be some differences. For example, if a systematic review is focused on a specific intervention or a population of people with a particular impairment or activity limitation, then it may be important to consider involving people with relevant specific lived experience.

The 7Ps framework (Concannon et al. 2012), shown in table 1, can be a useful framework for identifying who to involve. Although it has been developed for a US situation, and for involving people in identifying and prioritising outcomes for research on an intervention's effectiveness, the principles can be applied in other parts of the world, and in other types of research.

Table 1 The 7Ps Framework to help identify who to involve in health research (Concannon et al. 2012 edited)

Category	Description
Patients and the public	Current and potential consumers of patient-centred healthcare and population-focused public health, their caregivers, families, and patient and consumer advocacy organisations
Providers	Individuals (for example, nurses, physicians, mental health counsellors, pharmacists, and other providers of care and support services) and organisations (for example, hospitals, clinics, community health centres, community-based organisations, pharmacies, emergency medical services agencies, skilled nursing facilities, schools) that provide care to patients and populations
Purchasers	Employers, the self-insured, government and other entities responsible for underwriting the costs of healthcare
Payers	Insurers, Medicare and Medicaid, state insurance exchanges, individuals with deductibles, and others responsible for reimbursement for interventions and episodes of care
Policy makers	The White House, Department of Health and Human Services, Congress, states, professional associations, intermediaries, and other policy-making entities
Product makers	Drug and device manufacturers
Principal investigators	Other researchers and their funders

In deciding who to involve it is important to consider the aim of the PPI and, therefore, the range of perspectives that are needed to meet that aim. For example, if the aim is to have general oversight of the review conduct, then perhaps, people with a general perspective need to be involved. But if the aim is to identify the outcomes of greatest importance to people with lived experience of a particular health condition, then it will be essential to involve people with relevant lived experience. Often, for PPI, what is of greatest importance is that the people involved have a lived experience of a particular health condition. Generally, knowledge or familiarity with research methods and technical terms is not a requirement for involvement. It is good practice to write a role specification that describes, in plain language, the experience or attributes that people you involve should have. Also consider the potential benefits for people who volunteer to get involved in a systematic review, and make these clear. For example, these could include payment, authorship, acknowledgement, training, or impacting on an area of research that is important to them. The [National Institute for Health Research \(NIHR\) webpage on people in research](#) has examples of descriptions of people sought to involve in health research.

How to recruit people

After identifying the key groups of people to involve, strategies are required to find relevant individuals to approach and invite to get involved. The chapter on how to recruit and support patients and the public, and overcome barriers to their involvement in guideline development highlights different ways of identifying and reaching out to patient and public groups. Two broad strategies commonly used to find people to be involved in systematic reviews are:

- An open recruitment strategy, in which opportunities for involvement are advertised to the general population, and anyone can volunteer to get involved (for example, advertising on the [NIHR's People in research webpage](#)). Open strategies can be:
 - Fixed: After a group has been formed, advertising ceases and no new members are added.
 - Flexible: Advertising for new members is ongoing and group membership can fluctuate. This may mean that a series of workshops has different group members, or some group members may attend more than once.
- A closed, or targeted, strategy, in which individual people, or individual groups, are invited to be involved. There are several strategies for recruiting a targeted group:
 - Invitation: People known by name (or reputation) to the researchers will be invited to get involved. This can also be described as 'nomination'.
 - Existing groups: Rather than recruiting specific named individuals, the membership of an existing group is invited to get involved. Because different groups vary in how they operate, this can impact on the membership. In some cases, a group may have closed membership (that is, the same individuals make up the group), and sometimes a group may have open membership (that is, the group membership changes over time).

- Purposive sampling: A qualitative research framework is used for recruitment, generally aimed at getting representation of people with key pre-determined characteristics, experience or expertise. Although this results in a ‘targeted’ group, with closed membership, the strategies for identifying the population from which to sample can be similar to those for open involvement (that is, advertising).

How many people to involve

How many people you involve in your systematic review will depend on several factors. A key factor is the aim of PPI and, linked to the aim, how you are going to involve people (see the [section on how to involve people in a systematic review](#)).

The factors listed in the [section on choosing who, when and how for your review](#) will also influence decisions about how many people to involve. The numbers to involve will also depend on the different groups of people that you want to have represented (see the [section on who to involve in a systematic review](#)). Work in partnership with the people you involve to ensure that they are comfortable with the number and range of people involved. When small numbers of people are involved, for example, as members of a steering or advisory group, ask them if they feel they can represent the different viewpoints, or whether additional input is required.

In an exploration of PPI in a range of systematic reviews, Pollock et al. (2018) found that for:

- face-to-face meetings, the number of people involved ranged from 2 to 27
- one-off events, often advertised as open to the general public, the number of people involved ranged from 15 to 81
- involvement that did not require a face-to-face meeting, for example using an electronic Delphi or survey, the numbers invited ranged from 29 to 340 people.

When to involve people in a systematic review

PPI at stages of the systematic review

A systematic review is a process involving a series of different stages. The [Cochrane review ecosystem](#) illustrates 11 key stages of a systematic review, from developing the question through to writing and publishing the review. A final, 12th, stage is disseminating the results of the review. People can be involved at any (or all) of these stages. There should always be a clear aim or objective associated with involvement of people within a systematic review. Often the aim will relate to decisions that need to be made within the systematic review process. Depending on the aim of involvement, people may be involved at 1 stage, at 2 or more stages, or they can be involved throughout the whole review.

The [Cochrane Involving People learning resource](#) provides examples of systematic reviews that have involved people at the 12 different stages of a review process in order to meet a range of different aims. Table 2 provides some brief examples of PPI at different stages of systematic reviews, taken from the Involving People resource.

Table 2 Examples of involvement of people at different stages of systematic reviews (from the [Cochrane Involving People learning resource](#))

Stage of review	Example review (reference)	Aim of involvement	What happened?
1. Develop question	Edwards et al. (2015)	Clarify the review questions in a systematic review relating to complex mental health needs and services for children and adolescents in the UK	Edwards et al. (2015) used 2 different strategies. In 1 strategy, 6 young people who had been mental health inpatients, were interviewed, individually. The aim was to identify topics for the review to focus on. In the second strategy, healthcare professionals, young people and charity representatives met face to face to generate and rank topics of importance.
2. Plan methods	Pollock et al. (2015)	Clarify methods for a Cochrane review update relating to physiotherapy for people who had experienced a stroke, in particular the categorisation of interventions	Pollock et al. (2015) formed a stakeholder group of patients, carers and healthcare professionals. There were 2 meetings that focused on clarifying methods of the planned review. The stakeholder group's input generated a method for categorising interventions within the review. This method was used to structure the final review and also informed subgroup analyses.
3. Write and publish protocol	Liabo (2013)	Agree the protocol content for a review focused on interventions to support looked-after children in school	Liabo (2013) used a participatory approach to involve a group of young people throughout the review. At one of the meetings, participants were presented with a pre-prepared document with tick-box options for different alternatives within the protocol. The options had been generated from the discussions at previous meetings that focused on the review question. The text included in the final protocol reflected the views that had been collected during the tick-box exercise and associated discussion.
4. Develop search	Rees et al. (2004)	Advise on terminology for the search strategy, for a systematic review relating to HIV-related sexual health for men	Rees et al. (2004) involved a range of people in 3 meetings. In one of the meetings, the group specifically advised on terminology for the search strategy.

Stage of review	Example review (reference)	Aim of involvement	What happened?
5. Run search	Harris et al. (2016)	Help identify unpublished papers, for a realist review relating to community-based peer support	Harris et al. (2016) established an advisory network of stakeholders. Communication with the advisory network occurred through a series of events, as well as less formal communication, including email. Harris et al. report that advisory network members helped to identify relevant unpublished papers during the searching phase.
6. Select studies	Vale et al. (2012)	Provide oversight to a Cochrane review of chemoradiotherapy for cervical cancer	Vale et al. (2012) formed a group of 'patient research partners' who provided continuous oversight for the review. The group was actively involved in several review tasks, including tracing the address details of trial investigators for studies selected for inclusion.
7. Collect data	Bayliss et al. (2016)	Co-produce a coding framework for the qualitative analysis in a qualitative systematic review focused on predictive testing for those at risk of developing a chronic inflammatory disease	Bayliss et al. (2016) had a group of 'patient research partners' who provided continuous oversight for the review. Three of the patient research partners volunteered to be involved in the qualitative analysis. They coded themes for a random selection of 3 papers and contributed to developing a co-produced coding framework in collaboration with the researchers. This was done through email correspondence. Written training documents were developed to support the volunteers with this involvement.
8. Assess risk of bias	-	-	There is little evidence of involvement of stakeholders in the process of assessing risk of bias. Liabo (2013) reported that 'none of the young people were interested in being involved in activities that required them to read the full studies'. As a result of this observation, these stakeholders were involved in 'a general discussion about research quality rather than aiming for them to take an active part in reading the studies and assessing them for quality'.

Stage of review	Example review (reference)	Aim of involvement	What happened?
9. Analyse data	Bayliss et al. (2016)	Consider and comment on the qualitative themes generated for the qualitative synthesis	The patient research partners involved in the review of Bayliss et al. (2016) attended a face-to-face meeting to which all stakeholders were invited. They read all the included papers before the meeting. Bayliss et al. reported that this session aimed to help researchers draw on the perspectives of the patient research partners when interpreting and reflecting upon the data.
10. Interpret findings	Pollock et al. (2014, 2015)	Gain consensus on the clinical implications arising from the review	Pollock et al. (2014, 2015) held a stakeholder meeting at which the draft findings (results of meta-analyses) were presented. Stakeholders were asked to discuss the clinical implications of these findings. Through discussion, the group agreed the wording of a series of statements relating to clinical implications, with anonymous voting used to confirm agreement with the statements. The agreed statements were included with the published review.
11. Write review	Colcannon et al. (2014)	Get feedback on drafts of a systematic review of methods of stakeholder engagement in research	Colcannon et al. (2014) held 2 face-to-face meetings with a group of stakeholders, who also participated by email and phone throughout the review process, including commenting on tables, figures and manuscript drafts. Colcannon et al. stated that 'stakeholders [at a second meeting] also helped us identify effective ways to communicate the findings in tables and figures for this manuscript. All stakeholders were invited to participate by email and phone throughout the research, including a review of the manuscript'.

Stage of review	Example review (reference)	Aim of involvement	What happened?
12. Publishing the review and disseminating	Hyde et al. (2017)	Plan and contribute to disseminating the results of a review focused on factors affecting shared decision making around prescribing analgesia for musculoskeletal pain	Hyde et al. (2017) held 3 stakeholder meetings at different stages during the review. Group members were involved in 'planning how to share results' and 'agreeing dissemination of the results'. Consequently, 'results were targeted at practitioners, as [stakeholders] felt this was most important'. Hyde et al. reported that group members 'participated in dissemination of the review findings'. They also reported that they 'planned their own roles...including giving presentations and contributing the patient's perspective to discussions at conferences'.

Top and tail approach

Pollock et al. (2019) explored when systematic review authors had PPI in their reviews. They found that people were most commonly involved at the initial stages (stages 1 to 3: framing the question and planning the review) and the final stages (stages 10 to 12: interpretation, publication and dissemination of findings). It was less common for people to be involved during the middle stages (stages 4 to 9: conducting the review). Often people were involved at both the initial and final stages, but not in the middle – this has been termed a 'top and tail' approach (Pollock et al. 2019). A top and tail approach may involve the same group of people at the start and end of the review, or it may involve 2 different sets of people.

For systematic reviews being planned and conducted as part of the development of a guideline, a top and tail approach could potentially fit efficiently within the guideline process. However, there is no evidence to support this as being the 'best' approach, and decisions about when to involve people should be made based on the pre-determined aims of involvement for each individual systematic review.

How to involve people in a systematic review

Approaches to involvement

There is no evidence to show that any one way of involving people in a review is more or less impactful. Several different factors will influence the decision on the best approach for a specific systematic review. These factors may include the topic of the review, time available, resources available, and expertise of the review team.

Two different approaches to involvement have been used for other systematic reviews:

- Continuous involvement – people are involved ‘throughout’ the review process, perhaps as a member of the review author team or an advisory group.
- One-time involvement – people are involved at a specific stage in a review in order to complete a specific task or address a specific aim. For example, a group of people might be involved in discussing and reaching consensus on the question for a review, or people might be involved in order to contribute to the writing a plain language summary.

The aims of the PPI will help determine which approach might be best for a specific review. For example, if a key aim is to ensure that the outcomes included in the review reflect those that matter most to people affected by a particular health condition, then a one-time involvement approach may be more advantageous. This could enable a group of people to come together and reach consensus on the outcomes for the review. However, if the aim of involving people is to provide general oversight to the review process and ensure that all stages of the review process consider the views of patients and the public, then continuous involvement may be more advantageous. Some systematic reviews combine both approaches. For example, they may have PPI input on an advisory group throughout the review process, and then also plan 1 or more one-time events to get additional input into key stages of the review.

Levels of involvement

Involvement of people in a systematic review can be considered as a continuum, from more involvement and control, to less involvement and control. Pollock et al. (2019) explored the different tasks and activities in which patients and the public were involved in a range of systematic reviews. Using an iterative process, they developed a new taxonomy relating to the actions, responsibilities and tasks of those involved, called the 'ACTIVE continuum of involvement'. It describes people as leading, controlling, influencing, contributing or receiving (see table 3).

Table 3 The ACTIVE continuum of involvement (from Pollock et al. 2019)

Level of involvement	Tasks
Leading: Initiating the review; lead responsibility for carrying out and completion of review.	Tasks will include authorship of a review, and may include any activities associated with review completion, including key decisions relating to the methods and execution of the review.
Controlling: Working in partnership with researchers, with varying degrees of control or influence over the review process. Making decisions, controlling, or both, 1 or more aspects of the review process, in collaboration with or under the guidance of the review authors.	Tasks may include defining outcomes of interest, inclusion criteria, key messages arising from review findings and writing a plain language summary. In completing tasks people have control over final decisions, such as application of inclusion criteria, categorisation of interventions, or recommendations for clinical practice.
Influencing: Stating, commenting, advising, ranking, voting, prioritising, or reaching consensus. Providing data or information that should directly influence the review process, but without direct control over decisions or aspects of the review process.	Tasks may include assisting with review tasks, such as hand searching, screening, data extraction and assessment of risk of bias, possibly in a co-reviewer role. Tasks may include peer review, such as commenting on a protocol, systematic review or plain language summary.
Contributing: Providing views, thoughts, feedback, opinions or experiences. Providing data or information that may indirectly influence the review process. People may be participants in a research study (for example, focus groups or interviews).	Tasks may include sharing views or opinions, for example, within a focus group or interview. May include ranking, voting or prioritising as participants in a research study (for example, in a Delphi study).
Receiving: Receiving information about the systematic review, or results of the review.	Tasks may include attending events or reading or listening to information about the review. Although the results of a review may be discussed, these discussions do not influence the review process in any way.

Although the level of involvement of people in a systematic review can be seen as a continuum, there is no evidence of a hierarchical association between level, impact, benefit or success of involvement. Indeed, current evidence and opinion suggests that different levels and methods of involvement may be useful at different stages in a systematic review. What is important is to consider the level of PPI involvement, and their level of control or influence over the process. Decisions about the level of control that people will have at various stages in the review process should be stated in advance, ideally within the systematic review protocol.

Format of involvement

Format of involvement means the ways in which people interact and communicate, such as through face-to-face meetings, events or workshops, individual or group telephone or video-calls, or email and written communication. The format of PPI in a systematic review will depend on several factors. These factors include (but are not limited to) the aim of involvement, the people who are being involved, and the resources and time available for this. In an exploration of the format of involvement adopted in a range of systematic reviews, Pollock et al. (2018) found that direct face-to-face interaction was the most common approach, and that this might comprise a small meeting, a larger workshop or public event, or a combination of these. In most cases, between 1 and 4 meetings or events were held throughout a review, although as many as 20 meetings had been held. Meetings varied in length from 1 hour to half a day. A small number of systematic reviews used electronic or remote methods to involve people. Most commonly, this was an electronic Delphi or survey method, usually involving 2 or 3 rounds of voting.

Research methods and processes

A range of different ways have been used when involving people in a systematic review. Often these methods and processes involve different ways of sharing thoughts and ideas, such as group discussions or written feedback. Several formal research methods have also been used when involving people. Adopting a formal research method or process can be useful when there is a clearly identified role, or aim, for the people involved. For example, the aim might be to reach consensus on the outcomes of relevance to the review, or to agree a way to synthesise the evidence so that it is accessible and understandable.

Formal research methods and processes that have been used when involving people in systematic reviews include:

- Participatory research approaches: Include ‘action research’ and ‘participatory action research’ and are usually considered as ‘approaches’ to research, rather than methods. These approaches integrate PPI with qualitative research, with a joint process of knowledge production by researchers and patients or the public. Participatory research approaches have key tenets: a democratic impulse; iterative data collection and analysis, and simultaneous contributions to science, improvement and change.

Box 1 Example of a participatory research approach

For a realist review of community-based peer support, Harris et al. (2016) used participatory approaches to gain stakeholder involvement throughout the review. An advisory network was formed, comprising a range of different types of stakeholder. Recruitment to the advisory network took place throughout the review, and different individuals had varying levels of involvement, and at different stages. Some members contributed on multiple occasions and others on only a single occasion. A total of 12 meetings were held throughout the review, providing approximately 240 face-to-face contacts with around 120 stakeholders. In addition, there were also email discussions and opportunistic contact with researchers.

- Consensus decision-making techniques: Include using techniques for voting (that is, to make decisions about the review) and ranking (for example, to prioritise domains, such as outcomes, within a review). It also includes the nominal group technique, which involves a structured discussion and rounds of voting to reach consensus on a specific problem or issue, and the Delphi method, which involves several rounds of questionnaires or surveys to achieve consensus.

Box 2 Example of a consensus decision-making process

For an update of a Cochrane review relating to physiotherapy for people who had a stroke, Pollock et al. (2014, 2015) formed a stakeholder group comprising physiotherapists, stroke survivors and carers. During a series of 3 meetings, stakeholders made several decisions relating to the review. Decisions were made using the nominal group technique. In each case, the stakeholder group members first discussed a topic or statement for an agreed amount of time. Then each stakeholder group member individually ranked their agreement with that topic or statement and noted their reasons for this. The 'voting' sheets were anonymous, but were then collected and counted in front of the group members in order to see whether or not there was consensus on a topic. Further rounds of discussion and voting took place when needed.

- **Group process:** Often the process of involving people within a systematic review entails a group meeting, which may be called a meeting, workshop or conference. These meetings commonly involve discussion and debate, perhaps supplemented with formal methods such as consensus decision-making techniques. The content and processes within these group meetings are often poorly reported. However, evidence suggests that these meetings do often combine careful planning and use of techniques known to enhance the group process. The planning and approach to running group meetings provides a way of addressing many of the general issues identified as important to involvement, such as effective communication, clarity, expectations, respect and trust.

Box 3 Resource on group process

The [Agency for Healthcare Research and Quality Practice's Facilitator's Guide to Running Effective Meetings](#) provides a guide to key issues associated with planning and facilitating a group meeting.

- Qualitative research methods: These methods, such as interviews or focus groups, have been used to elicit views and opinions of patients and the public in relation to systematic reviews. The purpose has most commonly been to ‘contextualise’ the findings of a systematic review to a particular population or area. These data have then been analysed using methods for analysis of qualitative data, such as thematic analysis (Bunn et al. 2015, Martin et al. 2015). In such cases, the involvement of people has occurred after completion of the systematic review. However, it could be argued that the involvement relates to the final stages of a systematic review process (such as dissemination and translation of evidence into practice). The level of involvement is one of ‘contribution’ and, in these examples, the people involved could arguably be described as ‘participants’ in research.

Describing and reporting PPI within a systematic review

It is good practice to report who, when and how people have been involved in a systematic review, and to reflect on the impact that this had on decision making and the final outputs of the review. This section presents 2 ways to aid reporting on PPI.

The ACTIVE framework

The ACTIVE framework (Pollock et al. 2019) provides a way of describing how and when people were involved in a systematic review. The framework, mentioned in the section on [levels of involvement](#) and shown in table 4, lists a series of framework constructs that should be reported and proposes categories for classifying how people were involved.



Table 4 ACTIVE framework for describing involvement of people in a systematic review (adapted from Pollock et al. 2019)

Framework constructs	Categories	Notes
Who is involved?	<ul style="list-style-type: none"> • Patients, carers and their families • Patients, carers and their families, and other stakeholders • Other stakeholders only 	<p>The ACTIVE framework provides a way of categorising who is involved, using 3 broad categories.</p> <p>A written description should also be provided, giving numbers of people, and key information (for example, length of time with the health condition).</p>
How are people recruited?	<ul style="list-style-type: none"> • Open, fixed • Open, flexible • Closed, invitation • Closed, existing group • Closed, purposive sampling 	<p>The ACTIVE framework provides a way of categorising the way in which people were recruited, using a series of categories based on the method of recruitment.</p> <p>A written description should also be provided, describing the targeted individuals or organisations, as well as where those recruited came from.</p>
When are people involved?	<ol style="list-style-type: none"> 1. Develop question 2. Plan methods 3. Write and publish protocol 4. Develop search 5. Run search 6. Select studies 7. Collect data 8. Assess risk of bias 9. Analyse data 10. Interpret findings 11. Write and publish review 12. Knowledge translation and impact 	<p>EACH stage at which people are involved should be clearly stated.</p> <p>The aim of involvement at each stage should be clearly stated.</p>
When are people involved?	Top and tail approach?	<p>If a top and tail approach is used this should be clearly stated, again stating the level of involvement at each point at which people are involved.</p>
How are people involved? Approach?	<ul style="list-style-type: none"> • One-time involvement • Continuous involvement • Combined involvement (that is, both one time and continuous) 	<p>The categorisation of the approach to involvement gives a simple way of summarising what happened in terms of involving people in the review. Further details about what happened at each different stage at which there is involvement should also be provided, as outlined in the row on how people are involved, level of involvement.</p>

Framework constructs	Categories	Notes
How are people involved? Level of involvement?	<ul style="list-style-type: none"> • Leading • Controlling • Influencing • Contributing • Receiving 	For each stage at which people are involved, the level of involvement or control should be stated (see the ACTIVE Continuum in table 3 for definitions of levels and descriptions of tasks completed within each level). The level of involvement may vary at different stages in the review process.
How are people involved? Format and methods?	<ul style="list-style-type: none"> • Direct interaction • No direct interaction 	The categorisation of the format of involvement gives a simple way of showing the format of the involvement. It is important to also provide a description of what happened during any interaction. Details of the number and length of the interactions should also be reported. Note whether any formal research methods and processes have been used, and if so, what these were.

Several icons have also been developed, which may be useful for ‘labelling’ the PPI within systematic reviews. These icons are shown in table 5.

Table 5 Icons relating to the ACTIVE framework for describing involvement of people in a systematic review

Framework constructs	Categories	Icon
Who is involved?	Patients, carers and their families	
Who is involved?	Patients, carers and their families, and other stakeholders	
Who is involved?	Other stakeholders only	
How are people recruited?	Open, fixed	
How are people recruited?	Open, flexible	
How are people recruited?	Closed, invitation	
How are people recruited?	Closed, existing group	
How are people recruited?	Closed, purposive sampling	
When are people involved?	Top and tail approach?	
How are people involved? Approach?	One-time involvement	
How are people involved? Approach?	Continuous involvement	
How are people involved? Approach?	Combined involvement (that is, both one time and continuous)	
How are people involved? Approach?	Direct interaction	
How are people involved? Format and methods?	No direct interaction	

The GRIPP2 checklist

The GRIPP2 (Guidance for Reporting Involvement of Patients and the Public 2) checklist (Staniszewska et al. 2017) is a guideline for reporting PPI in health and social care research. It is not specific to systematic reviews, and it aims to capture reflections relating to the impact of involvement, in addition to the methods, and other components. There is a long and short-form version. The long form includes 34 items on aims, definitions, concepts and theory, methods, stages and nature of involvement, context, capture or measurement of impact, outcomes, economic assessment, and reflections. It is suitable for studies in which the main focus of the manuscript is PPI. The short form includes 5 items on aims, methods, results, outcomes, and critical perspective and is suitable for studies in which PPI is a secondary focus (for example, to briefly describe the PPI approach used within the manuscript describing the broader study). Although not specific to systematic reviews, the GRIPP2 checklist may provide a helpful guide for reporting the methods and impact of PPI and could be applied to a systematic review.

Resources for planning and conducting PPI in systematic reviews

[Cochrane's Involving People](#)

A resource for systematic review editors and authors to support them in getting people involved in producing reviews. It is open access with a free Cochrane account.

[Stakeholder Engagement in Evidence Synthesis](#)

Open access resources related to engaging with stakeholders during planning, conducting and communicating evidence syntheses.

[Cochrane's Consumer involvement training](#)

A collection of resources for those who want to involve consumers in producing systematic reviews.

[Webinars from the International Network for Patient and Public Involvement](#)

A series of open access recordings of webinars about engagement and involvement in an international context, including Stakeholder Involvement in Evidence Synthesis, by Dr Neal Haddaway.

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References

- Bayliss K, Starling B, Raza K et al. (2016) [Patient involvement in a qualitative meta-synthesis: lessons learnt](#). Research Involvement and Engagement 2: 18
- Bunn F, Sworn K, Brayne C et al. (2015) [Contextualizing the findings of a systematic review on patient and carer experiences of dementia diagnosis and treatment: a qualitative study](#). Health Expectations 18(5): 740–53
- Cochrane Community. [Cochrane Review Ecosystem](#) [online; accessed 4 December 2020]
- Cochrane Consumer Network (2017) [The Statement of Principles for Consumer Involvement in Cochrane](#)
- Concannon TW, Meissner P, Grunbaum JA et al. (2012) [A new taxonomy for stakeholder engagement in patient-centered outcomes research](#). Journal of General Internal Medicine 27(8): 985–91
- Concannon TW, Fuster M, Saunders T et al. (2014) [A systematic review of stakeholder engagement in comparative effectiveness and patient-centered outcomes research](#). Journal of General Internal Medicine 29(12): 1692–701
- Edwards D, Evans N, Gillen E et al. (2015) [What do we know about the risks for young people moving into, through and out of inpatient mental health care? Findings from an evidence synthesis](#). Child and Adolescent Psychiatry and Mental Health 9: 55
- Harris J, Croot L, Thompson J et al. (2016) [How stakeholder participation can contribute to systematic reviews of complex interventions](#). Journal of Epidemiology and Community Health 70(2): 207–14
- Hyde C, Dunn KM, Higginbottom A et al. (2017) [Process and impact of patient involvement in a systematic review of shared decision making in primary care consultations](#). Health Expectations 20(2): 298–308

- Liabo K (2013) [Service user involvement in research: Collaborating on a systematic review with young people who have experience of being in care](#). Doctoral thesis. London: Institute of Education, University of London
- Martin S, Fleming J, Cullum S et al. (2015) [Exploring attitudes and preferences for dementia screening in Britain: contributions from carers and the general public](#). BMC Geriatrics 15: 110
- Pollock A, Baer G, Campbell P et al. (2014) [Physical rehabilitation approaches for the recovery of function and mobility following stroke](#). The Cochrane of Database Systematic Reviews 4: CD001920
- Pollock A, Campbell P, Baer G et al. (2015) [User involvement in a Cochrane systematic review: using structured methods to enhance the clinical relevance, usefulness and usability of a systematic review update](#). Systematic Reviews 4: 55
- Pollock A, Campbell P, Struthers C et al. (2018) [Stakeholder involvement in systematic reviews: a scoping review](#). Systematic Reviews 7: 208
- Pollock A, Campbell P, Struthers C et al. (2019) Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews. Journal of Health Services Research & Policy 24(4): 245–55
- Rees R, Kavanagh J, Burchett H et al. (2004) [HIV health promotion and men who have sex with men \(MSM\): a systematic review of research relevant to the development and implementation of effective and appropriate interventions](#). EPPI-Centre, Social Science Research Unit, Institute of Education, University of London: London
- Staniszewska S, Brett J, Simera I et al. (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ 358: j3453
- Vale CL, Tierney JF, Spera N et al. (2012) [Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment](#). Systematic Reviews 1: 23